

• *Information dissemination.* All agencies of the Public Health Service engage in information dissemination, but the largest single institution with this function is the National Library of Medicine. Additionally, the NCHSR disseminates its research findings to approximately 3,000 agencies and individuals in the form of research activities reports.

I believe that the Public Health Service provides valuable services in three areas: (a) in primary data collection for use by others doing technology assessment; (b) in the development, validation, and continuing evaluation of methods for assessing technologies; and (c) in continuing to provide HCFA with assessment of health care technologies.

The activities that I have described are rather circumscribed, however, and they should be supplemented by professional associations and others.

I believe that PHS activities in technology assessment must be linked with research in health services delivery. Medical technologies cannot be evaluated effectively unless they are examined within the environment where they are used. Furthermore, the function of technology assessment should properly draw upon the knowledge and skill of those at the National Institutes of Health; Alcohol, Drug Abuse, and Mental Health Administration; Food and Drug Administration; and the Centers for Disease Control.

Over the last year we have been reevaluating what the role of the Public Health Service should be in technology assessment. Questions we have asked are: Should we assume full responsibility for technology assessment in this country? I think not. Should we assume greater regulatory authority over the use of new technologies? Again, I think not.

In response to the first question, new information is being developed at too great a pace and over too wide a spectrum of clinical medicine to leave the assessment process solely to the Federal Government. I also believe that the medical profession, manufacturers, and third-party private payers need to participate.

In answer to the second question, the PHS is not in a position to make decisions about who should receive a particular technology, or who should provide that technology, or where the technology should be provided. It is our responsibility to provide the best clinical and scientific information about new medical technologies to the Health Care Financing Administration and to the public. We have that responsibility because of the need for the

Federal Government to maintain a responsible stewardship over the Medicare trust fund. We also have a responsibility to administer faithfully the regulatory laws over drugs and devices. Beyond that, I believe that it is the responsibility of the private sector to make its own decisions about the purchase and use of new technologies.

I believe that technology assessment in this country would be best served by a private-public partnership. To this end, the National Center for Health Services Research has recently begun to develop a plan to clarify and strengthen the PHS role in technology assessment. We are also working with the Institute of Medicine to plan for a consortium within the private sector to assess medical technologies. We continue to be optimistic that such a consortium will emerge, and we look forward to cooperating in such a venture.

A public-private partnership in technology assessment would also take advantage of the important work already done by such groups as the American College of Physicians, American Medical Association, and the American College of Cardiology. The continued participation of these organizations in technology assessment is critical. The PHS cannot and should not duplicate the valuable and important role of these groups. A heavy-handed Federal role, whether perceived or real, has not worked in the past and it will not be accepted for the future.

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### **Meeting the Health Care Needs of Children with Disabilities: A Progress Report**

In an earlier editorial in this journal (*1*), I discussed a Surgeon General's Workshop convened in December 1982 to address the problems and needs of children with handicaps and their families. Participants included not only national experts in pediatrics, rehabilitative medicine, nursing, health care administration, third-party reimbursement, health planning, and health care financing, but handicapped patients and their families as well.

Two days of deliberation resulted in seven major recommendations from the workshop participants for action to address the special needs of children with disabilities. Many activities, projects, and publications were stimulated by the workshop, building on some initiatives already in progress. Now, a year and a half later, it seems appropriate to report on some of these efforts as they relate to the specific workshop recommendations.

1. *Define the scope of the problem.* Following a 2½-year policy analysis of the problems of disabled children by the Vanderbilt University Institute for Public Policy Studies, the university and the Institute of Medicine in April 1983 cosponsored the National Conference on Chronic Illness in Children, which greatly increased public awareness and understanding of the scope of the problem. Another project in this area has been carried out by the Institute for Health Policy Studies of the University of California at San Francisco. Staff of the institute are now analyzing data from their investigation of an increase over the last two decades (as reported in the National Health Interview Survey) in the proportion of children whose activities are limited by chronic illness.

2. *Develop models and standards.* The necessity for developing models and standards that address family needs is being met in several ways. Michigan State University, focusing on diabetes management, is developing comprehensive standards for a regionalized network of community health support. Objectives of a project at the University of Iowa include determination of an organizational framework to define individual health care interactions, development of principles of care to serve as guidelines for those interactions, description of standards to guide the delivery of specific health care services for children with disabilities, and publication and dissemination of the results.

3. *Develop systems of regionalized care.* Staff of projects in Illinois, Louisiana, and Maryland are developing systems of regionalized care for ventilator-dependent children. All three projects focus on the transfer of children from institutional settings to home or homelike settings and emphasize the need to develop and sustain a community-based support system. Efforts to provide comprehensive health care to children with rheumatic diseases are continuing at six regionalized centers in Colorado, Georgia, Hawaii, Illinois, Ohio, and Texas. The centers feature a combination of resources such as university-based pediatric rheumatology clinics, local chapters of the Arthritis Foundation, State Crippled Children's Services, and local health care professionals. A networking project at Georgetown University, emphasizing community-based services, is providing consultation and technical assistance to approximately 20 States to promote resource sharing and collaboration among agencies serving disabled children. This effort is jointly sponsored by the Public Health Service and the Department of Education's Office of Special Education and Rehabilitative Services.

4. *Improve financing of care.* Improving financing of care for children with disabilities is critical to ensure that

the needs of these children can be met with the limited resources available. In May 1983, the Information Sciences Research Institute sponsored a meeting addressing concerns identified at the Surgeon General's Workshop. The meeting, which brought together health care providers, public and private insurance payers, policy-makers, and representatives of voluntary agencies, led to the formation of subgroups that are pursuing these issues. Participants at an October 1983 meeting hosted by the private insurance industry discussed the feasibility of a "high risk pool concept" for financing care of chronically ill and disabled children. A number of other meetings have also been held, bringing together a wide variety of persons interested in improving health care financing for children with special needs. These meetings have been marked by participants' excitement and enthusiasm in sharing innovative ideas and strategies.

5. *Identify areas of potential abuse.* Methods for identifying areas of potential abuse are incorporated in efforts, already outlined, to develop model standards and systems of regionalized care.

6. *Incorporate principles of care for children with disabilities in training curriculums for health professionals.* In July 1983, the Department of Pediatrics of the Albert Einstein College of Medicine sponsored a conference on "Education of Pediatricians for the Ongoing Care of Children with Special Health Needs." Five necessary roles of pediatricians were highlighted: coordinator, educator, advocate, provider of continuity of care, and counselor. Participants discussed ways of enhancing training of pediatricians for these roles in this specialized area of care; the role of the pediatrician as a health team member; and involvement of the pediatrician with the community, with advocacy efforts, and with public policy. A report on the conference has been sent to all participants, chairpersons of all pediatric departments, selected foundations, and other interested parties.

7. *Support research on the care of children with disabilities.* In assessing the current status of research on the care of children with disabilities, the National Institute of Child Health and Human Development (NICHD) is reviewing the previously mentioned policy analysis by the Vanderbilt University Institute for Public Policy Studies. Interagency collaborative efforts in this area continue between the Health Resources and Services Administration's Division of Maternal and Child Health and NICHD, the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases, the National Heart, Lung, and Blood Institute, and the National Institute of Neurological and Communicative Disorders and Stroke. In addition, the National Institute of Mental Health issues a monthly bulletin on research conducted on the

problems of children and adolescents with chronic and severe emotional disorders. The National Institute for Handicapped Research, in the Department of Education, has funded two projects with a focus on the problems of chronically ill and disabled children. One of these is a workshop on "Youth in Transition," to be convened in Minneapolis this summer, and the other is a project at the University of Connecticut to establish a research and training center focusing on children in need of habilitative services. The National Center for Health Services Research has funded a study to assess the trends and determinants of chronic illness in childhood through detailed analysis of existing data from the National Health Interview Survey, the National Health and Nutrition Examination Survey, and the U.S. Bureau of the Census. In fiscal year 1983, 15 of the 65 proposals submitted to the Division of Maternal and Child Health for funding related to children with chronic illness or disabling conditions. A number of these proposals were stimulated by the Surgeon General's Workshop.

I am grateful to the staff of the Division of Maternal and Child Health, who planned, convened, and sup-

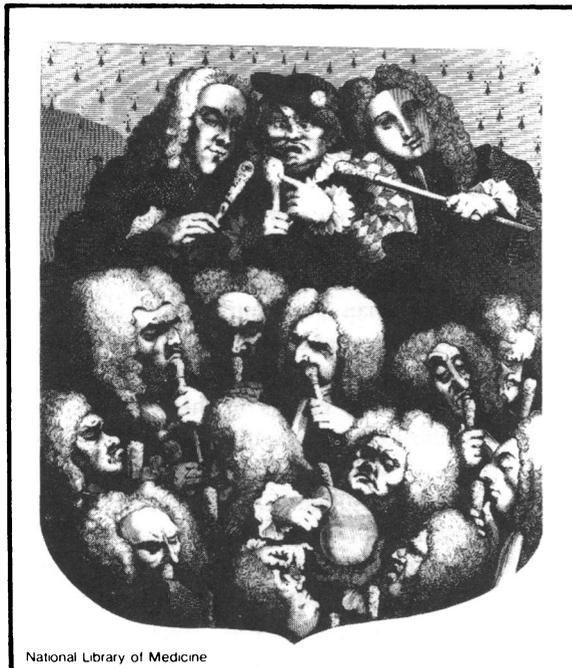
ported the Surgeon General's Workshop; supervised the writing and dissemination of the final report (2); carried out many of the recommendations; and recently prepared a followup report for the participants.

The record of activities I have outlined shows that we are still a caring and compassionate society. I am proud, as a public servant and as Surgeon General, that we are making a difference in the lives of many hundreds of children and their families.

C. Everett Koop, MD, ScD  
Surgeon General

**References** .....

1. Koop, C. E.: Meeting the health care needs of children with disabilities [Editorial]. *Public Health Rep* 98: 105-107, March-April, 1983.
2. *Public Health Service: Report of the Surgeon General's Workshop on Children with Handicaps and Their Families.* U.S. Government Printing Office, Washington, D.C., 1983.



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